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ABSTRACT

Described are residential and educational services provided for mentally retarded (MC) children and adults in Sweden. Normalization is the focus of the services which make maximum use of mental and physical capacities to reduce the handicap of mental retardation. Described are general principles, and four stages involving development of services (diagnosis, specialization, differentiation, and decentralization). Administrative facts and regulations are explained in terms of authorities responsible, legislation, and planning of services according to legislation. Discussed in a section on epidemiology and etiology are aspects such as early identification of the MR, causes and additional handicaps, incidence, and trends (indicating a decrease in number of cases of children and increase of adult cases). Principles of residential care which are discussed include community group homes, social adaptation, single room provision, provision for small heterogeneous groups, and integration by sex. The following are among services described: special schools and boarding homes for children, preschools and nurseries, vocational education, residential homes for children and adults, standards for residential facilities, day care services, sheltered workshops, and services for leisure activities. Explained are individual rights of MR persons, costs of care, and responsibility of authorities in safeguarding rights of the MR. Discussed are ancillary services such as nursing care, child psychiatry, and pediatrics; and noted are trends toward normalization of services. (MC)

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The Mentally Retarded in Sweden

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To RICHARD STERNER, *father and fighter*

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General principles and historical background

Aims and principles

The basic aim of all services provided for the mentally retarded in Sweden is *normalization*. The principle of normalization is applicable alike to the development and handling routine of the retarded individual (child or adult), to the function of institutions, and to the actual organization of services etc.

Differences in people's capacity to adjust to society are purely quantitative, and even the most severely handicapped person can be "normalized" in one or more respects.

The validity of the principle is not negated by the fact that the majority of retarded people cannot become fully adjusted to society. The term implies rather a *striving* in various ways towards what is normal. This applies also to the work of institutions; in fact, the entire system of care, as such, can be "normalized".

Normalization does not imply any denial of the retarded person's handicap. It involves rather exploiting his other mental and physical capacities, so that his handicap becomes less pronounced. It means also that the retarded person has the *same rights and obligations* as other people, so far as this is possible.

There are, of course, mentally retarded persons who should not be forced out into society, for humanitarian reasons. However, these most severe cases of mental retardation must not, as previously, determine the sort of help given to the majority.

In this context, there has been increasing emphasis in recent years on "integration". Integration, however, relates primarily to the technical and organizational possibilities of coordinating services for the mentally retarded with other social services, and seeing to it that the mentally retarded receive their particular assistance among other people, and not in isolation from them. Integration, in other words, is a means towards normalization, not an end in itself. One negative consequence of over-integration, for instance, can be to isolate the retarded person still more in respect of friendships and social contacts.

Mentally retarded people require a succession of supportive measures of a medical, pedagogic, psychological and social character. These various forms of assistance must usually be provided for a very long period, in many cases for life. Necessary conditions for adequate care are that support and assistance

should be forthcoming at an early stage, and that the child, young person or adult should receive such support and assistance in a manner that encroaches as little as possible on his life and family. This means that in the future only a carefully selected group of retarded people will have to be cared for at a residential home or hospital, permanently or for a given period.

The purpose of service to the *individual* is to create an harmonic and socially adjusted person (in some cases the "social" group concerned will be very small). This involves helping him to reach the emotional maturity and stability that we now know can develop in spite of mental retardation. Social adjustment is demonstrated by meaningful work at a due rate of payment, and it is promoted by the greatest possible freedom during leisure time, and in the process of daily living. Every attempt should be made to achieve the following aims:

a) retarded persons should live in as normal a way as possible, with their own room, and in a small group;
b) they should live in a bisexual world;
c) they should experience a normal daily rhythm;
d) they should eat in a small group, as in a family, with food and drink standing on the table;
e) they should work in an environment different from that in which they live;
f) they should be paid for their daily activities and trained systematically to handle their money by themselves;
g) they should be able to choose between different ways of spending their free time;
h) their pursuits should be individually designed, and differentiated according to the time of year;
i) the environment should be adjusted to the age of the retarded persons;
j) retarded young people should be given the opportunity to try out adult activities and forms of life, and to detach themselves from their parents.

For the principle of individual normalization to succeed, the following requirements must be made of any *institution* in which retarded people live:

a) that it be organized on the principle of the small group, i.e. not more than ten persons living and eating together, preferably four to eight;
b) that the physical standard of the institution reduces collective facilities to a minimum, i.e. in respect of toilets, basins and showers, bedrooms, etc.;
c) that the institution be situated within a community;

d) that the institution should not be larger than will permit the assimilation of those living there into the local community;

e) that the social contacts of the institution be freely developed in both directions;

f) that those living there be offered alternative domicile at weekends and at holiday times;

g) that the institution should consistently work in cooperation with relatives and the retarded persons themselves.

Within the organization it must always be possible to exchange any given form of care for a less rigorous one. This can only be achieved if one and the same authority has the ultimate and total responsibility. Private or voluntary efforts must, therefore, be subordinated to and coordinated with the commitments of the public sector.

Legal capacity and the right of self-determination are fundamental rights and should only be circumscribed in explicit aspects. This should be the case irrespective of where the retarded person is living.

The retarded person has a right to self-expression, participation and acceptance. This includes the right to be listened to, even if he cannot express himself in a conventional manner, to make choices and to become accepted by and integrated into the community. He also has a right to shelter in the community of his own choice, so as to minimize the need for institutionalized care.

It is not a utopian idea to propose that the retarded themselves organize demonstrations or associations to promote their interests. In Sweden, national conferences have been initiated for the mentally retarded, at which they themselves formulate their demands and desires (see p. 36).

It is on the basis of these principles that the care of the mentally retarded is built up and differentiated in Sweden. The principles are warranted not only clinically, but also for humanitarian, rational and economic reasons.

Four stages in the development of provisions and services

All types of provision for the handicapped seem to pass through certain specific stages of development. The first stage—which in Scandinavia started a century ago—involves identification of the problems encountered by a specific group of individuals. This stage we can call the *diagnostic stage*.

The second stage is one of *specialization*, as particular needs are met by special solutions specific to those needs. This leads to a centralization of services; a single institution, for example, may be decided upon for the whole country,

or for a specific region. This second stage is dominated by specialists, to whom the consumers of services must subordinate themselves; the other needs of the handicapped thus become of secondary interest to the experts.

The third stage we can call that of *differentiation*. At this stage it is realized that a particular service cannot be standardized for all recipients. Factors affecting differentiation include the need for an interplay between medical, educational, and social specialists, and the degree of retardation. The Nordic countries are currently at the stage of differentiation.

Finally, provisions for individuals with different handicaps will reach the fourth, and what we regard today as the last, stage. This is a composite process characterized first by a *decentralization* of services, followed by provision for the *integration* of services to the handicapped with those similar services which the non-handicapped individuals receive from the community. This stage we have only begun to formulate and tackle. The decentralization and subsequent integration of community services presuppose a sufficiency of trained personnel in a given geographical area, a transportation system for the handicapped, and a general state of readiness and relative open-mindedness among the population.

Historical background

Even if the education and care of the mentally retarded started in the Nordic countries about a century ago, development has been extremely slow. Only in the past two decades or so we have achieved any sort of systematic service.

Characteristic of early development was that it concentrated exclusively on the child—the child as a symbol of future progress. And only the "educable" were helped. The more severe cases had to wait. This seems to have been the case with all types of social care: the most active, those who could make their voices heard and demonstrate, have been catered for first. Bed patients and others unable to make their voices heard have had to wait until last.

Among the Nordic countries, it was Denmark that took the lead. Under a strong influence from Central Europe, special psychiatric hospitals for the mentally retarded were built on a large scale during the early decades of this century. Sweden's first special hospital for the mentally retarded was opened in 1930. Norway and Finland developed somewhat later.

Schools and institutions were created above all by private individuals and foundations, but with time the County Councils, and finally the state, took steps. The creation of "idiot schools" dominated at first, but the difficulty of placing pupils from special boarding schools in the community led to the opening of residential homes for adults in conjunction with the schools. Special

children's asylums were also frequently built in connection with the schools. In 1895 there existed in Sweden 19 idiot schools, 6 boarding homes and 8 asylums for children or adults.

An important factor in promoting the development of care has been the Swedish National Association for Retarded Children *(Riksförbundet för utvecklingsstörda barn)*, which was created in 1956 (see p. 57).

Administrative facts and regulations

The authorities responsible

The central administration of provisions for the mentally retarded is divided between the Ministry of Social Affairs, the National Board of Health and Welfare and the National Board of Education. Decisions by the two Boards can always be brought to the Government's consideration by an appeal. Political and administrative staff serve primarily in the Ministry, the professional staff serving with the Boards.

Broadly speaking the two Boards deal with control, planning and quality-setting. They cannot lay down in detail the duties of the County Councils since these have their own constitutional powers, and are also rating authorities (claiming on average 9 % of the taxpayer's income).

There are 23 County Councils proper, two County Borough Councils in the two cities of Göteborg and Malmö, and the Municipal Council of the island of Gotland which functions as a County Council. The counties are of varying size, with populations ranging from 58,000 to 424,000, with an average of 250,000. The Stockholm County Council, a special case, answers for a population of 1,500,000.

A County Council, whose members are elected by the public every three years, is responsible for local government in respect of health protection and medical services, public dental care, children's homes, certain kinds of vocational training, rehabilitation, and all provisions and services for the mentally retarded. The County Council meets at least twice a year for sessions lasting for three to five days. Budgets are approved at these times, and general policy guidelines laid down for the coming year's activities. Administrative and executive power is vested in the County Council's Board of Administration.

57 % of the total income of the County Councils comes from local taxes,

13 % from state contributions, and as much again from charges. Of their expenditures, 8 % goes to provisions and services to the mentally retarded.

Legislation

A new Act on Provisions for Mentally Retarded Persons[1] came into power on 1 July 1968, superseding previous legislation dating from 1954.

The word "provisions" has been used to mark a broadening of the services required by the mentally retarded to cover not only teaching and nursing care, but also social services, counselling, day activities, etc.

The first paragraph of the Act defines the concept of "mentally retarded"; the Act is concerned with those who by reason of retarded mental development require "special" provisions from the public sector in their education, their adjustment to society, or otherwise. The term mental development relates to the intellectual functions. No specification is given of the degree of retardation; in considering a case, attention should be paid above all to the existence of an actual need for the measures covered by the Act. Even if it is thus desired to keep application of the Act very flexible, this does not mean that action under the Act can be taken in respect of persons whose intellectual function is not greatly impaired. Particular caution in this respect is prescribed when persons are required to enter a residential home or hospital against their will.

Generally speaking, the classification of mentally retarded persons in Sweden has so far been somewhat narrower, than, for instance, in Denmark and in the United States. In respect of I.Q., a limit has traditionally been set at about 70, according to traditional tests, but this limit is very flexible and the I.Q. as such has in general been accorded less importance as more tests have become available. Testing is in any case only part of the "overall assessment".

The term "special" provisions is used for measures taken in accordance with the Act on Provisions for Mentally Retarded Persons, as distinct from measures taken in accordance with, e.g., the Social Welfare Act or the Medical Care Act.

The Act does not cover all mentally retarded persons. Many retarded people can meet the requirements made of them by society without special help, perhaps not throughout their lives, but at least for certain periods. The most difficult years are those at school. At no period of our lives are the intellectual demands made upon us as great as then. Thus, roughly twice as many persons per annual cohort are helped through the Act during these years as during the years before and after.

[1] *Lag angående omsorger om vissa utvecklingsstörda*, see the Swedish Code of Statutes (SFS) No. 940, published on 31 January 1968

The Boards for Provisions and Services to the Mentally Retarded

The Provisions Act prescribes that the activities of the County Council in this field shall be handled by a Board for Provisions and Services to the Mentally Retarded, and that this Board shall include a director of schools for the mentally retarded, a director of care for the mentally retarded and a medical director.

Full-time medical directors serve at present in practically all counties. The special hospitals and largest residential homes, of course, also have full-time physicians. By comparison, however, with Denmark, the Netherlands and the United Kingdom, relatively few medical practitioners are engaged in work with the retarded. Nor does it exist as a specialty.

The Boards for Provisions and Services usually employ also various specialists, e.g. psychologists, social workers, occupational therapists, leisure time supervisors, teachers and nursing staff. The number of psychologists employed has increased from only a few in the early 60's to about 75 at the time of writing. The Board for Provisions and Services to the Mentally Retarded is far more than an administrative body. Its task is generally to ensure that the mentally retarded within the County Council area are provided with such services as they need; at the same time, it is to plan, coordinate and develop the necessary facilities in a satisfactory manner. It consists as a rule of 6—8 politically elected persons, meeting usually once a month. The legislation stipulates also that the Board should give a representative of the parent associations the opportunity to be present at such meetings, or otherwise provide suitable information concerning its activities to such associations.

Associated with the Board is a Decisions Committee, the chairman of which is a qualified lawyer. These Committees deal with certain matters relating to commitment to and discharge from schools and institutions, leave of absence, etc. The parents, and the retarded persons themselves, have the right to be present at meetings to state their case.

Planning services for the mentally retarded under the Act

The Swedish legislation on services for the mentally retarded is comprehensive. This means that, with the exception of certain general provisions such as those contained in the social security legislation, a single Act enumerates all the mandatory and various forms of special services to be provided for the retarded. The current Act lays down the County Council's total obligation to those retarded who, because of their limited intellectual development, are in need of special services for their education, social adjustment or for other reasons.

At an ordinary hairdresser's — the principle of normalization in action

The responsibility for implementation of the Act lies with the National Board of Education and the National Board of Health and Welfare. These two Boards have officials representing the fields of medicine, pedagogics, psychology, social welfare and jurisprudence with regard to the mentally retarded. Their duties are not only advisory and consultative, but include inspection visits to the individual institutions.

However, pressure from above is not always sufficient in itself to activate the County Councils; it is equally necessary to have some kind of pressure coming

from below, from those representing the "consumers". The latter are the only people who can describe in detail all the services actually required by the mentally retarded.

If the parent associations wish to be in a position to criticize and influence the County Council, then it is in our opinion wrong for these associations actually to run institutions. In Sweden, the associations, with one minor exception, neither own nor run any institutions.

The planning process for services for the mentally retarded, as provided by a County Council, follows much the same lines as the planning of other health and medical services. Naturally, occasional differences of opinion arise between the Board for Provisions and Services to the Mentally Retarded and the government agencies which approve actions and grant funds. In this respect, however, the Boards are greatly aided by the fact that no other group in Sweden has its social, pedagogic and medical needs and rights so firmly and in such detail prescribed in law.

By the terms of the legislation, County Councils are required to make out a plan over their services for the mentally retarded. This plan shall indicate the schools and various institutions—including those for daytime activities—that the Council runs or intends to set up, stating their geographical position and the number of persons they can receive. Such plans are mostly approved for five years at a time by the National Board of Education and the National Board of Health and Welfare.

When plans have been ratified and activities approved, state grants are made for the erection and conversion of buildings. Such a grant usually amounts to SKr 9,000 per person.

Epidemiology and etiology

Information, case-finding and registration

It is in the interest of the Board for Provisions and Services to the Mentally Retarded itself to reach the retarded as soon as possible. This can apply also to adults who manage for the most part very adequately, but who still need help of some particular kind.

The Act on Provisions for Mentally Retarded Persons therefore requires the Board actively to ensure that retarded persons get the services they need. It

1 SKr (Swedish Krona) = approx. US $0.21 or £0.09

would be impractical, however, for the Board itself to perform case-finding; impractical because the officers of the Board have no chance of reaching out into the field with the sort of "radar" apparatus needed. It would also be irrational, since case-finding should not only cover the mentally retarded but also handicapped children and young people of all kinds. The Board for Provisions and Services must therefore cooperate on this matter with child psychiatry and other hospital departments for children, child welfare centres, county and municipal medical officers, district nurses, kindergartens and parent associations. All these are thus required to inform the parents of the situation and their rights under the Act.

All children are now delivered at maternity wards. We calculate that 90 % of newborn children are examined by a child doctor. 99 % of children up to the age of 1 are then registered with a child welfare centre, which involves visits to the home by nurses, and several visits to a doctor. The number of children so registered subsequently falls off, particularly after the age of 2, to approximately 67 % at the age of 5.

The essential feature of the registration procedure is that malformations observed immediately after birth are reported upon monthly, by a verbal diagnosis or description. The frequency of different malformations is thus kept under continuous surveillance.

A new register system will be coming into force during 1974, by which all newborn will be reported within one month in respect also of other diseases and handicaps.

All newborn children in Sweden are examined for phenylalanine. A constantly excessive concentration has been found in one of 21.000 children examined. Subsequent examinations of these children have revealed that 50—60 % have classical phenylcetonuria. This means a frequency of real phenylcetonuria among newborn Swedish children of one in approximately 35.000.

A total health check-up of all 4-year-olds was introduced in 1971, although it has not yet been arranged in all counties. The check-up given covers, for instance, vision and hearing, a dental examination, and an examination of mental development. For the purpose of this latter there is a special questionnaire which a nurse fills in from discussion with the parents, primarily in the home. Some of the questions put have a particular bearing on mental retardation. Obviously, it is the mildly retarded children who are traced in this age group, mainly by their retarded linguistic development.

A new technique is now being investigated with a view to discovering some of the somatically non-handicapped but mentally retarded children at an earlier stage. The parents of children of the age of 18 months have been asked to assess the child's development for themselves, following a set form. Random

checks have suggested that such an assessment can be made fairly reliable.

Under the Provisions Act, the parents of retarded children have greater rights than the parents of other handicapped children. The Board for Provisions and Services is required to provide home care even to very small children. This has begun to function as a good means of contact with the parents, and it promotes cooperation between the different public authorities concerned. The special nursing allowance provided (see p. 51) has the same effect.

Causes and additional handicaps

For the causes assumed to underlie mental retardation, see Table 1. This presents an inventory made by Klackenberg of 352 retarded children between the ages of 12 and 15 in Stockholm, compared with a Danish study of all 13-year-old mentally retarded children in Copenhagen (87 persons), and an inventory made by Penrose covering both children and adults.

As shown by the Table, the cause of mental retardation is in most cases medical. The term polygenous or multiple gene is roughly equivalent to "constitutionally determined retardation". The most important thing is that we do not in Sweden reckon with socio-cultural factors as the only causes of mental retardation, even if such factors can contribute.

Table 1. Causes of mental retardation, summary

	Danish survey[1] %	Klackenberg[2] %	Penrose[3] %
Primary medical causes	54	47	42
Contributory medical causes	24	16	43
No causes	7	21	
Polygenous	15	16	15

[1] *Sociologiske Meddelelser*, 12. serie, 2. hæfte 1967/1968

[2] Karin Stensland Junker: *Samhällets samvetsbarn*, Stockholm 1964

[3] The Journal *Mental Subnormality*, Vol. XII, Part 2, No. 23, Dec. 1966

Special interest has been devoted to retarded people suffering from multiple handicaps. An inventory of these is given below.

Of the 35,000 mentally retarded in Sweden, known to the Boards for Provisions and Services, more than 4,350 (12.5 %) suffer in addition from one or more of the following serious handicaps: visual defects, hearing defects or motor incapacity (see Table 2).

Persons with visual defects. Of the 955 mentally retarded suffering from visual defects, 41 % are completely blind. More than half (52 %) are of compulsory school age, 7—21 years old (see p. 32). 60 % are seriously and gravely mentally retarded. There is an unequivocal connection between the degree of the visual defect and the level of retardation; only 14 % of those who can barely see are gravely retarded, as compared with 60 % of the completely blind.

Only just over 60 % of those suffering from visual defects participate in some kind of daily activity (usually education or occupational therapy). The rest, almost without exception, are gravely retarded. On average, 85 % of all mentally retarded persons participate in daily activities in Sweden.

Persons with hearing defects. The age structure of the 488 mentally retarded suffering from hearing defects is largely the same as that of the normal population.

Only 36 % of all retarded persons suffering from hearing defects are gravely retarded (as compared with 60 % of those suffering from visual defects).

77 % of those with impaired hearing participate in daily activities, of whom as many as 14 % in sheltered work (as compared with only 6 % among those with visual defects).

Persons with both visual and hearing defects. The age structure corresponds to that of the mentally handicapped suffering from visual defects only.

As among those with visual defects, 60 % of all the 151 retarded with impaired vision and hearing are gravely retarded. Only 28 % of the men but no less than 52 % of the women are gravely retarded.

Persons with motor handicaps. 56 % of the 3,069 mentally retarded with motor handicaps are no more than 21 years old, only 4 % are of retirement age. The excess mortality is thus greatest in this category. No less than 67 % are gravely retarded.

86 % of the 3,069 mentally retarded with motor handicaps (i.e. 7.5 % of all known mentally retarded) are in need of wheelchairs. 5 % are completely confined to bed.

Only 28 % of all mentally handicapped persons suffering from motor handicaps participate in daily activities for three or more hours a day.

Discussion. These additional handicaps occur more frequently among the mentally retarded than among the rest of the population. In the case of hearing defects, however, the difference is not particularly great.

As regards the ratio between visual defects and hearing defects, the inventory reveals a discrepancy as compared with the ratio applicable to the non-retarded. Among the latter, hearing defects are three times as frequent as visual defects. Among mentally retarded persons the ratio is the reverse; there are twice as many persons with visual defects as with hearing defects (see Table 3). This strong connection between visual defect and mental retardation is probably due to the fact that the agent or trauma causing a brain damage is more likely to produce a visual defect than a hearing defect. This is indicated also by the strong connection between grave mental retardation and visual defects; no such connection exists in the case of hearing defects.

This also explains why the number of adults with visual defects is comparatively smaller than the number of children with visual defects, while the age structure among mentally retarded persons with impaired hearing is more uniform. The difference is due to excess mortality among the gravely retarded.

Table 2. Number of mentally retarded persons with certain additional handicaps, 1972[1]

Dwellings	Total number of mentally retarded persons	Visual defects	Hearing defects	Both visual and hearing defects	Motor handicapped	Total number with additional handicaps	
						Number	%
Residential homes, special hospitals	12,670	644	320	113	1,968	2,807	64
Parents' home, own home, group home	22,254	311	168	38	1,101	1,558	36
Total	34,924	955	488	151	3,069	4,365	100
Percentage of all mentally retarded		2.7	1.4	0.4	8.8	12.5	

[1] About 1 % suffer from two or more of the additional handicaps stated, 12.5 % from at least one

Table 3. Ratio between mentally retarded and non-retarded persons with visual and hearing defects

	Visual defects		Hearing defects	
	Number of pupils	Ratio	Number of pupils	Ratio
Non-retarded pupils of comprehensive school age	158	23	520	77
Mentally retarded of the same age	261	68	123	32

Bedridden cases

In 1971, an inventory of persons confined to bed during the day was made among all the 12,338 children, young people and adults living in Swedish institutions. It emerged that 126 were entirely confined to bed, which means 1 ‰ of the population. A comparison was made with the situation in Nebraska, USA, where 4 ‰ were bedridden.

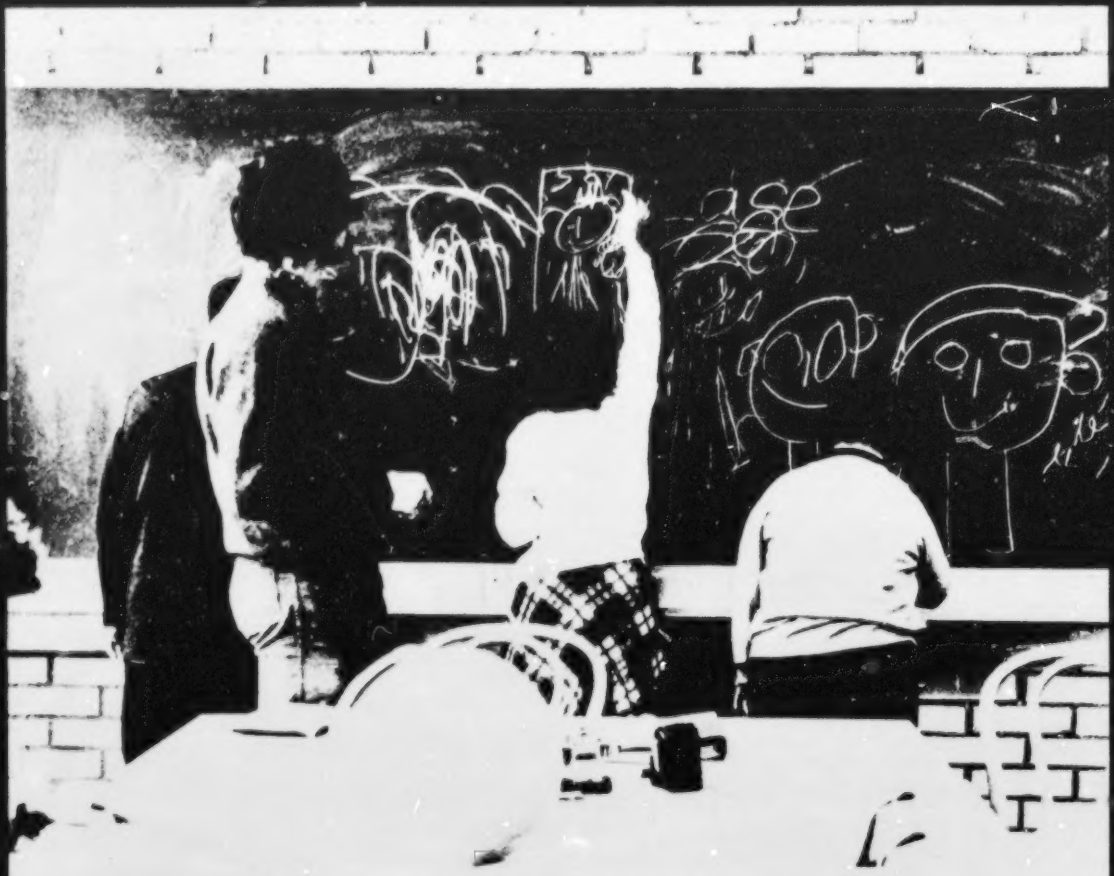
How many receive care?

As shown by Table 4, more than 35,000 retarded persons were known to the Swedish authorities in May 1973. This means that 0.43 ‰ of the entire Swedish population receive some form of help as being retarded.

The Table also shows how the proportion of male retardates is much higher (approximately 19,000 persons) than the proportion of females (less than 15,300). Almost 0.5 ‰ of males are known to be retarded; among women the figure is less than 0.4 ‰.

As shown by Diagram 1, the proportion of retarded people varies considerably between the different age groups. The majority of the retarded are not registered as being in need of special care until they reach the age of 6 or 7. The percentage of the total population amounts during compulsory schooling (to the age of 21) to almost 1 ‰ per annual cohort, subsequently falling gradually to zero.

Do these 35,000 include all the retarded persons in need of care? The answer, obviously, is no, since we are never likely to achieve a perfect case-finding system. Also, it would probably be a misplaced ambition to have all borderline



Scribbling can give as much satisfaction as writing

cases receive help and support via the organization for special care. By the principle of normalization, retarded people should receive, primarily, the same support as other citizens. And in the case, particularly, of children below the age of 7, a number are admittedly under treatment by a child doctor or psychiatrist as late developers; but it should be kept an open question whether they need help via the special organization.

Also, we must always remember that the term "mental retardation" is only meaningful in a context; particularly in the case of the mildly retarded, a great deal is decided by their individual environment.

Table 4. Number of mentally retarded persons as of 1 May 1973, in percentage of respective age group

Retarded persons				
Age	Male	Female	Both sexes	
			Number	%
0—4	451	405	856	2.4
5—9	1,602	1,169	2,771	7.9
10—14	2,479	1,671	4,150	11.8
15—19	2,684	1,863	4,547	12.9
20—24	2,585	1,809	4,394	12.5
25—29	2,149	1,768	3,917	11.1
30—34	1,473	1,190	2,663	7.6
35—39	1,168	913	2,081	5.9
40—44	976	839	1,815	5.2
45—49	1,017	795	1,812	5.2
50—54	966	839	1,805	5.1
55—59	764	637	1,401	4.0
60—64	655	570	1,225	3.5
65—69	475	395	870	2.5
70—74	271	267	538	1.5
75—79	116	108	224	0.6
80—84	45	41	86	0.2
85—89	14	10	24	0.1
90—94		2	2	—
95—99		1	1	—
Total	19,890	15,292	35,182	100
Percentage of population	0.49	0.38	0.43	

Diagram 1: Proportion of mentally retarded persons in the Swedish population as of 1 May 1973, by annual cohort

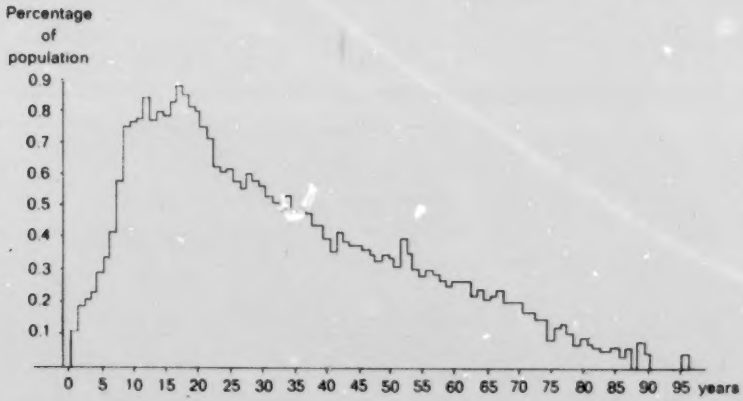


Table 5. Number of mentally retarded persons in the 25 County Council and Borough areas, 1973, in percentage of county population

County Council	%	County Council	%
Västernorrland	0.71	Örebro	0.44
Västerbotten	0.64	Västmanland	0.44
Gotland	0.60	Södermanland	0.43
Kristianstad	0.56	Halland	0.43
Kalmar	0.55	Älvsborg	0.42
Gävleborg	0.52	Värmland	0.42
Skaraborg	0.51	Uppsala	0.40
Kronoberg	0.51	Jönköping	0.38
Jämtland	0.49	Malmöhus	0.38
Kopparberg	0.48	Göteborg and Bohus	0.36
Blekinge	0.48	Malmö	0.35
Norrbotten	0.45	Stockholm	0.32
Östergötland	0.44		

The number of retarded people receiving care in the different County Council areas varies considerably (see Table 5). Some County Councils have twice as

many retarded persons as others. The former are more rural in nature, while the latter consist of the three big metropolitan areas. The difference is not due to any discrepancy in the development of services, but to a real difference in numbers. This is due, among other things, to the strong correlation, demonstrated by Åkesson (see ref.), between the rate of emigration and the number of retarded persons in a geographical area.

The total number of retarded people is considerably lower than in the majority of non-Scandinavian countries, even if the same definition is applied. This is probably due, above all, to the fact that cultural deprivation, malnutrition and comparable environmental factors are practically non-existent in Sweden.

Number of mentally retarded persons with pensions

Practically all those between the ages of 16 and 66 who receive services draw an invalid's pension (advance pension or sickness allowance). The mentally retarded with a pension comprise 0.54 % of the total population in the 16—66 age bracket.

If we consider, for instance, the number in relation to others receiving pensions during their youth (16—19 years) we find that retarded persons comprise 71 % of the total, i.e. that three out of four young people entering adulthood with a severe handicap are mentally retarded. This is a very strong argument for increased efforts on behalf of mentally retarded children.

There is a fairly high turnover among those drawing a pension. Some die, others can manage for a while without a pension but return later in life. According to Sterner (see ref.), it can be estimated that the risk of a person of 15 becoming eligible by reason of mental retardation for an advance pension or temporary sickness allowance before he dies or attains the age of 67 approaches 1 %.

Is the number of retarded persons increasing or falling?

The number of still-born children has continued to fall in recent decades, as has the infant mortality rate. This means a relatively large increment of children, in a ten-year period, who survive pregnancy, delivery and the first year of infancy. Many believe this to have been achieved at the expence of an increased number of children with permanent brain injuries, even if the number is relatively small.

On the other hand, we are now acquiring new and steadily improving methods of preventing brain injury during pregnancy, delivery and infancy.

Then there are the favourable results noted in the early habilitation of injured children, medically, psychologically and pedagogically. These methods benefit all injured children.

There is thus clear evidence that the number of injured children has already been reduced. The number of children with cerebral paresis, for instance, has fallen significantly in the 60's.

As regards the hereditary forms of mental retardation, we know that those depending on specific injured genes are more frequent in marriages between relatives than otherwise, and consequently occur more frequently in geographically isolated areas. Sture Rayner[1] has shown that such diseases have fallen by 50 % in the space of 30 years, thanks to the way in which the isolation of the Swedish population has been broken up.

Polygenous mental retardation can also be expected to decline, as geographical isolation is overcome. Rayner, in the same article, shows how the number of mild cases has fallen to one quarter of what it was in a given municipality in the late 40's. Considerable gains are surely still to be made in this respect.

So far we have seen a considerable increase in the number of adult retarded persons, owing to the greater life expectation.

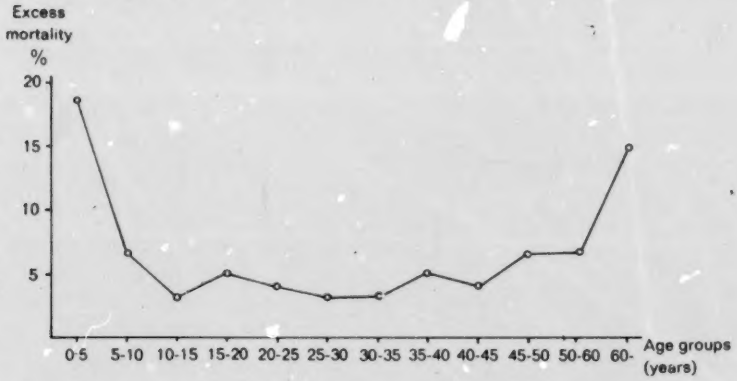
Larsson and Sjögren, 1954, and Akesson, 1962 (see ref.), have, from two different materials, calculated excess mortality among the mentally retarded at between 30 and 40 %. Forssman and Akesson, 1968, studied length of life in 12,903 retarded children and adults investigated 1955—1959[2]. These were practically all retarded people living at the time in an institution, or attending a special class. The results are shown in Diagram 2. The total group noted a mortality rate 5 % above normal. With deep, severe mental disturbance, excess mortality amounted, among both men and women, to 7 %, being concentrated to the 0—10 age group (11 %) and to those over 60 (20 %). Among mild cases, excess mortality is 1 % for men and 2 % for women. In other words, length of life is practically normal in the case of mild and uncomplicated mental retardation. Data have also been calculated for different diagnostic groups.

The most important reasons for the increased length of life are probably the introduction of antibiotics, improved standards of hygiene at the institutions, with smaller departments and bedrooms, a higher standard of diet, etc. Obviously, this development will influence the number of adult retarded people very strongly in coming years.

[1] The journal *Psykisk Utvecklingshämning*, No. 1/1966

[2] Proc. of the 2nd Cong. of the IASSMD, Warsaw 1970

Diagram 2. Excess mortality in 12,873 subjects with severe mental deficiency, by age



Principles of residential care

Services must be planned on the basis of the normal community. The flow and development of increasingly comprehensive services should be from without the institution to within, not from within and out towards society. This means that the specialists organizing services and supervising staff must not be tied to institutions. All services for retarded persons must be regarded as of equal importance, and the priority for 24-hour-a-day services to those in residential homes must be abolished. The development of care at home, and other kinds of day care, will then benefit. This concept of serving the retarded persons in the community also means that we should assign greater responsibility to all kinds of specialists whose skills we can use in our provision of services, and as far as possible buy such services instead of building up a specialists' service of our own.

The dynamics of living

We are building up, in Sweden, large numbers of fairly small units, located in the middle of the community, which are more or less specialized for the functional level and current needs of retarded people. This means that the retarded individual, as he progresses, will have to move more often than previously.

Movement is regarded as a disadvantage by many people, who think it good for the retarded person to live and remain in one place for his entire life. We ourselves, however, often experience an economic or personal development and renewal when we change our place of work or residence. And this experience should not be specifically restricted to the non-handicapped.

We try, when designing services for the retarded, to separate residence, occupation and leisure time. The same formula is applied, as far as possible, to 24-hour institutions for the retarded. We try, for instance, to put a geographical distance between the school and the residential home, and between all other types of living and the daily occupation. This also means that we want as far as possible to use the local community's leisure and recreational facilities. Our goal is to have retarded people spend their leisure time out in the community, preferably on an individual basis, otherwise in groups.

Principles for the size of institutions for residential care

In determining the ideal size of institutions for the mentally retarded, the authorities responsible follow the principles outlined below. The following factors *favour* relatively small institutions:

a) Greater proximity is possible to the retarded person's own home town and relatives. This is an important and often decisive factor in the rehabilitation of retarded persons. It allows more visits, better emotional ties with people and things outside the institution, and more frequent periods (hours, days, weeks or months) outside the institution.

b) It is easier to integrate the institution socially and geographically within the community. Larger institutions require such large closed-off areas that they tend to be excluded from the community.

c) Both the retarded person himself and the community regard him as less "odd" and his handicap as less severe, thanks to the wider social contacts made possible in accordance with a) and b).

The following factors argue *against* small institutions:

a) The number of retarded people does not "warrant" certain technical facilities such as gyms, swimming pools, sheltered workshops, dental care, etc.

b) The number of residents is too small a basis for differentiated care, specialist examinations, and the employment of staff specialists, either full-time or as consultants.

c) The staff feel isolated and do not have the same opportunities for teamwork, further training, etc.

It is quite clear that the advantages of the small institution are so great that everything must be done to enable the majority to be cared for in such institutions. It is thus important that the mentally retarded receive residential care which involves a minimum encroachment upon their freedom to develop, but which is still sufficiently effective. For this reason, cases must be screened so that the relatively few who require a greater degree of specialized care and comprehensive facilities receive them, but at the regional level; these facilities will thus have a much larger catchment area—in the case of the special hospitals, several County Council areas.

The person or institution responsible for caring for a retarded person will, in a properly organized system, never lack the necessary assistance: there will always be a back-up facility, a next step to which the person can be referred, and where care of a more specialized nature will be available. Naturally, the final, or regional level will have no form of back-up facility. However, this level will have at its disposal the resources for a maximum effort; also the number of retarded persons being screened to this level will be relatively small.

As a result of this firm structurization into levels, only 3 % of all children are cared for at a special hospital. The others live in residential homes or boarding homes that are socially geared, and not run primarily on hospital lines.

Residential care and social adaptation

Good social adaptation presupposes transfer training, and transfer demands a small and stimulating environment. Individualized, well-structured, and meaningful influence techniques are required for the handicapped individual to achieve the greatest benefit from the stimuli of a small environment.

The milieu of application must be a socially real and concrete environment. It is impossible to build up substitute situations within institutions. The retarded individual needs training in a situation identical to that in which he is going to function. This means that we must offer our severely retarded persons social environments and situations in which they can apply freely and in a natural manner what they have learned in the specific instructional situation. This is an important consideration when determining where in the community a group home or residential home should be located.

The greatest opportunities for training are provided by daily life

The own room

The need of mentally retarded people, other than children, to have their own room has previously been underestimated. We know from our own experience how we identified ourselves with our own rooms, their furniture and walls, and how the whole room became part of us. The mentally retarded today have very limited opportunities to understand themselves, but they *can* do so in a way from the material around them—their room becomes part of them, they are able to build up a sense of identity; their ego and individuality mature through the room, and through the things they collect and like to have around them.

If one compares a mentally retarded youngster with a room of his own with a similar boy of the same age and functional level living in a boarding school or

hospital, one soon sees the difference. It is practically impossible to build up all that an individual requires in the crowded atmosphere of an institution. We have learned, too, that aggressive young people tend to calm down, and begin to feel more secure, if they are taught to live in a room of their own, with their own possessions.

The overall proportion of single rooms in residential facilities in Sweden is 48 %.

The principle of the small group

Those working in institutions have long since observed that severely retarded individuals appreciate a "small environment", in which the number of interactions with other people are few. Many workers have observed the positive effect on a severely retarded individual of transfer from a large ward of 20—30 persons to a small group of 10 or less (5—8 would be preferable). The retarded person's reactions suddenly become predictable, and he can recognize and grasp reality. Observations such as these have led psychologists to formulate the "principle of the small group".

From these observations we deduce that an influence for favourable development is to be found partly in the small number of interpersonal relations forced upon the retarded person, thus making them potentially stimulating rather than frustrating, and partly in the homelike atmosphere and equipment of the room, and of the unit to which the room is connected.

The homeliness—or homelikeness—may need to be modified when one considers certain more or less permanent medical needs, and such technical arrangements as are necessary to provide a suitable environment for individuals with certain additional handicaps.

What is important when planning for residential living is that the starting point be an environment that is normal, homelike and small.

Certain research has been performed, following the small group principle. Before the wards were designed for a new department at a special hospital, a test ward was constructed for six severely retarded adults. Intensive training in the small group appreciably reduced the amount of work by staff.

Heterogeneous groups

In a guided environment, interpersonal relations among residents play a leading role, and are perhaps more important even than relations between residents and staff. The necessary condition for a favourable environment is that the com-

position of the small group—i.e. those living together in a unit (ward)—be carefully planned. Within the limits of the overall grouping (children, adults), the small group must be as heterogeneous as possible. This philosophy is in opposition to that of segregating those with physical handicaps, the blind etc., into special units. The distribution of these "minorities" over all units reduces the number of multi-handicapped persons in each unit, and gives them a richer and more active environment than otherwise. For this to be possible, however, enough specialists and specialized services must be available, and the ward must be properly equipped to deal with the additional handicaps. Groups which may necessitate a departure from this fundamental principle are deaf adults and school-age children.

The most retarded persons should always be in a minority within the group so that they may be "drawn upwards" by the other group members. The span of retardation should not be greater than for group activities to permit maximal benefits to the individual group member.

Sex and residential care

Previously, an effort was made to keep not only the different departments at homes for adult retarded persons monosexual, but entire homes. In the last ten years or so, policy has been the exact opposite. All homes are now approved for both sexes, and the majority of residential homes for adults are now bisexual. An inventory made in 1971 showed that 23 % of the different departments at these housed both sexes. The idea underlying bisexual units is that tolerance and general satisfaction with life should increase, and that the retarded will become calmer, and more interested in their appearance and behaviour.

73 % of group homes for adults (housing an average of seven persons) are bisexual, while a full 93 % of staff consider that these small homes should be bisexual.

Detailed interviews with adult retarded persons living at residential homes show that many of them experience great apprehension, sometimes anguish, when faced with sexual situations, owing to their ignorance and isolation.

Special teaching material on these matters now exists for adult retarded people, and others.

The services provided

Special schools and boarding homes for children

Practically every County Council has a boarding school for the mentally retarded, usually one built or converted in the past fifteen years. The number of places available at these has fallen recently, while the number of pupils at special classes for the retarded, attached to a regular school, has risen dramatically. Some doubt has been felt in educational circles as to the type of teaching demanded by these classes, owing to the wide spread in age and intellectual capability. In spite of this, special classes for both basic comprehensive teaching and training have been increasingly integrated with the regular nine-year compulsory comprehensive school; the fear that retarded children might be "persecuted" by other children has proved unjustified, provided the latter are given the right sort of information.

There are also two special boarding schools for mentally retarded children with difficiulties in social adjustment (one for boys and one for girls) plus one special boarding school for pupils with behavioral disorders. Finally there are a special school at a hospital, designed for mentally retarded children with severe orthopaedic handicaps, a boarding school for blind and another for deaf mentally retarded children.

Boarding homes for children with excessive distances to travel are now being built in ordinary residential districts, in semi-detached houses or blocks of flats. At best, such a boarding home consists of a group of up to six children living with a foster family in a detached residence. The children travel home on Friday evening, and return to the school on Monday morning. We now have about 70 boarding homes of this kind.

Results have been very encouraging, and all County Councils that are currently planning new boarding homes have preferred to link them to residential areas, rather than to the school.

Special education is no longer regarded as a purely pedagogic question, but rather as extending beyond the world of the school to training for life in the community at large.

By comparison with ordinary classes, a special class for the mentally retarded is smaller, has specially trained teachers, special teaching aids, and great liberty in respect of curricula. In principle, no time limit is set for the achievement of results in such schools. A school for the mentally retarded also has greater access to certain experts, including speech therapists, psychiatrists, psychologists and physiotherapists.

Creating — however simply — is always a pleasure

Are all retarded children in education?

Education is compulsory for all mentally retarded children from the age of 7 as long as they need it, up to 21. This means that schooling is compulsory even for the severely and profoundly retarded children.

How far has this programme been accomplished? 9,400 children and young people receive special teaching in class, and 1,700 receive separate teaching, which means in practice a maximum of five lessons a week.

In the 7—16 age group, there are about 100 children living with their parents, and 120 at residential homes, who receive no education. In the 17—21 age group, the corresponding figures are 150 and 80.

Which is better for the child—to live at home, or at a boarding home?

A number of studies have been made in this field, even if it is difficult to obtain comparable groups. In the case of children attending the special basic comprehensive school for the mentally retarded, studies have shown by and large a greater degree of social maturity on the part of those living at home, as compared with those living away. No other difference could be demonstrated.

In the case of those attending a training school, on the other hand, the reverse situation seems to hold: here, apparently, it is the boarding home form that tends to promote social development.

Nurseries and pre-schools

Day nurseries for mentally retarded children are designed to relieve parents of the burden of daily care. This applies above all to the smaller children, and to the more severely handicapped up to the age of 7. As a rule, the day nursery is combined with a pre-school. There are 60 such day nurseries, with 600 children. An effort is made to integrate also these children as far as possible in day nurseries for non-handicapped children.

Mentally retarded children below the age of 7 have the right to pre-school instruction. This right is not tied to any lower age limit. If no pre-school class is available in the district, a child has the right to five hours' teaching per week at home, from a primary school teacher. It is recommended that County Councils should primarily arrange these classes in integration with ordinary pre-schools, so that the children can continue to live at home. There are now about 125 independent classes and classes integrated with pre-schools for other children. A further 35 classes are combined with boarding or residential homes.

In total, some 1,300 mentally retarded children are taught at pre-schools.

67 % of them live with their parents, 20 % at residential homes, and 12 % at boarding homes.

The trend is increasingly towards the teaching of mentally retarded children in ordinary pre-schools. This may mean that the number of children in the class has to be reduced slightly, in order that one or two handicapped children can be taught together with them, usually with the help of a special assistant. Another necessary condition is that the pre-school teacher, who will usually have had very little training in dealing with handicapped children, should receive special guidance.

Education 7—17 years

The education of retarded pupils between the ages of 7 and 17 is divided into schools for basic comprehensive teaching and training schools.

A total of some 4,600 children between the ages of 7 and 17 receive instruction at a special basic comprehensive school. 75 % of the children live with their parents and 24 % at boarding homes.

The essential innovation in recent years has been the "training school". With the introduction of such schools in 1968, all retarded children were in principle required to undergo education. The upper intellectual limit for the placing of a pupil in a training school is a matter of practical pedagogics. No lower limit can be set as regards the pupil's ability to avail himself of teaching. The children concerned, however, should be sufficiently developed to follow, in some degree, collective or individual requests and commands. On the other hand, one cannot demand that all pupils should from the beginning, or even throughout their time at school, possess a sufficient command of speech as to be able to talk to the teacher or their classmates. The aim, of course, is to incorporate increasing numbers of severely retarded children into the training school. There are training schools at all residential homes for children.

The pupils at these training schools represent a wide range of different developmental disturbances. They are individually very different, and often—in spite of having the same physical age—at widely disparate stages of development. The training school, like the school for basic comprehensive teaching, is formally divided into different grades. In practice, greater importance is accorded to the division into departments (junior, middle and senior), than to biological age.

2,800 receive instruction at a training school. 50 % of them live with their parents, 24 % at residential homes, 23 % at boarding homes, 3 % at hospitals.

Table 6. Number of mentally retarded pupils in each class as of May 1973

Pre-school	4—7
Training school	4—8
Basic comprehensive school	6—11
Vocational education	6—11

Table 7. Distribution of the number of classes for retarded pupils as of May 1973

Classes in combination with boarding homes	385
Classes in combination with residential homes	200
Classes in combination with ordinary schools	530
Separate classes	270

Table 8. Number of pupils in education, in relation to forms of dwelling

Education	Form of dwelling		
	Parental home[1]	Boarding home[2]	Residential home[3]
Preschool —7 years	900	150	300
Special basic comprehensive school 7—17 years	3,600	950	50
Training school 7—17 years	1,450	550	750
Vocational school 17—21 years	950	850	250
Special (separate) education 7—21 years	350	—	1,300
Total	7,250	2,500	2,650

[1] including foster homes (500 children)

[2] including special boarding schools (125 children)

[3] including special hospitals (300 children and young people)

[4] 2,000 of these pupils live five days a week in boarding homes on the same grounds as the school, and 500 in group homes integrated in society

Vocational education

The law prescribes vocational education for all young people. The part of the system that is designed to give complete instruction in a given occupation is called *vocational training*, while that with the limited aim of training general working ability or skill in a wider field is called *work training*. Special vocational guides now offer assistance with practical employment orientation, and try in general to facilitate the transition to working life.

Retarded young people are required to attend vocational education until the age of 21, a period that can be prolonged until 23. It can be mentioned in passing that 90 % of all young people in Sweden receive some form of instruction for at least two years subsequent to the age of 16.

2,100 young people, the majority of them between the ages of 17 and 21, are receiving vocational education. Only 41 % of them are living with their parents.

Vocational education has been shown by experience to give good results, provided it is given in conditions that resemble as much as possible a normal place of work. Experience has also shown that failure to adjust to work is due more often to inadequate social training, rather than any inability to do the job. Increasing emphasis is therefore being given to training the pupil to live as independently as possible, and to preparing him to leave the parental home.

The goal set for vocational training is work on the open market, while the goal for vocational work is mainly work in a sheltered workshop, or an unqualified service occupation. Many, however, are expected to remain at day activity centres for the mentally retarded.

Special and separate teaching

Special teaching can be arranged either in a special class or parallel with ordinary instruction in the school for the mentally retarded. Special classes are arranged, for instance, for those suffering from hearing defects. Teaching parallel to ordinary class teaching is often called "clinic" teaching. The most usual case is the "speech clinic". Pupils taking part leave the class for a given period to receive special instruction from a speech therapist.

Only when school attendance is unsuitable or impossible, by reason for instance of a prolonged illness, should teaching be provided where the child lives or is staying. Such teaching is called *separate teaching* and consists of up to five lessons a week. 68 % of the 1,700 pupils who receive separate teaching live in residential homes, 20 % with their parents.

Handicap-awareness

Between the ages of 12 and 15 many young people start to become aware of their handicap. We must be prepared to help them to become aware of their handicap so that they are more able to share their problems with us, by discussing and analysing their behaviour and their feelings. The longer we delay in doing this the greater the crisis could be. In their process of development, children need new experiences to test themselves in order to be able to cope with the real-life situation when it occurs. We must help them to experience new situations and in this way we can point out to them their weaknesses and their strong points.

Study groups, folk high schools, national conferences

When they reach the age of about 20, many of the mentally retarded are motivated to acquire a knowledge of things they have previously been taught for years in schools. Many have for the first time a real motivation, for instance, to learn to read, write, or learn arithmetic. We have therefore developed what we call *study groups for the mentally handicapped.*

Many study groups for the mentally handicapped read subjects at primary school level, including Swedish, arithmetic and English. There are other groups for all kinds of study of cultural activities. The members meet, at the most, twice a week, and meetings last for up to three hours. In 1970, the largest study organization in Sweden ran 2,700 study groups for the mentally retarded.

Sweden's *folk high schools* were originally introduced for adults who did not, in their youth, have the opportunity or money to further their education. Most of them were run by voluntary organizations, religious or political. In recent years these folk high schools have begun to take an interest in the mentally handicapped, inviting them to special courses. We find that the most important aspect of this system is the contact between the ordinary students attending the schools and the retarded.

In the last four years, once a year, the Swedish National Association for Retarded Children has arranged *national conferences for young retarded adults.* Last year, 50 retarded young adults aged 18—30 took part, two from each county, accompanied by one young adult of normal intelligence from each county. They had previously been taught through a special study group at their home how to vote, chair a meeting, write a resolution, etc. The conference technique was for them to work in small groups, to discuss a topic and then meet to make a resolution, then repeat this procedure for the next topic.

Here are some examples of the content of the resolutions made: as regards leisure time, they wanted to be integrated with non-retarded people and not

segregated, and to go out in smaller groups; they thought their leaders decided too much for them; where vacations were concerned, they wanted more homogeneous age groups; they did not want summer camps or colonies for adolescents or for adults; and they wanted to travel to foreign countries. Where accommodation was concerned, they wanted to choose their own furniture. They did not want any fixed times in their boarding schools and residential homes. Where work was concerned, they insisted that their work capacity should not be underestimated, and that their colleagues at work should know about their handicap.

Residential homes for children

The majority of residential homes for children are approved for children from 0 to 17 years of age. To these homes are assigned those requiring more medical care than they can get in a boarding home.

Sweden has a total of 46 residential homes for 2,300 children, of which 12 are privately owned. (18 of these homes are incorporated with residential homes for adults.) The size of these institutions varies from 11 to 250 places, with an average of 50. The average number of children per department is 12, and 4.5 % live in rooms with 5—6 beds (all other in smaller units). 20 of Sweden's 25 County Councils and Boroughs have recently built or are building new homes for children.

A couple of homes receive children for short-term care, one of them operating only during the summer and catering for severe orthopaedic cases who are otherwise cared for in their own homes. It is also becoming increasingly common for ordinary residential homes to have places for short-term care. On average, the number is estimated at 200. Such places are integrated with ordinary places. The indication for short-term care is usually a need for rest on the part of the parents, but it has proved increasingly necessary to exploit the time spent there for observation and the setting up of new treatment for the child, treatment which is subsequently carried out at home.

Practically all the residential homes for children planned in recent years have been placed in or near a town with a general hospital, which means access to a pediatric and a psychiatric department for children and young people. Even in general, specialists have been engaged to an increasing extent as consultants to the residential homes.

Passive care has been transformed into active care. Methods now exist for the social training of even the youngest and most severe cases. For this policy to be consistently implemented, however, the participation of child psychologists and trained staff is required on a much greater scale than at present. For the somewhat older children, up to 7 years, there is kindergarten teaching, after which

the training school takes over with its systematic, goal-directed training, which in due course will cover all children. There is a shortage, however, of physiotherapists, speech therapists, and specially trained teachers.

The emotional isolation of residential homes for children is now being successively overcome. For decades, nursing staffs have identified themselves with their task in life, without the support of specialists, with no other aim than to provide the best possible nursing, and without contact with relatives other than in exceptional cases.

Aims and training programmes can now be defined for every individual child, and, as a rule, the parents maintain contact with their children, take some of them home over week-ends etc., and take the children with them on holidays. Conversely, children can be received for short-term care, in order that the parents can take a holiday or because the child needs it.

Previously, the line between a school for the mentally retarded and a residential home was drawn according to whether children were educable or non-educable. We know today that all children are educable, and that this is a matter which depends more on our demands and methods than on the ability of the child. Large-scale efforts during the early years can permit a major saving in staff etc. for the rest of the children's lives.

Table 9. Living conditions of all the mentally retarded adults receiving provisions and services as of 1 May 1973 .

Living condition	Number of retarded adults	%
Parental home	5,690	31.0
Own residence	1,320	7.2
Other private home (foster home, family care)	557	3.0
Boarding home	9	0.1
Group home	1,046	5.7
Residential home	8,194	44.6
Special boarding school	—	—
Special residential home	214	1.1
Special hospital	1,138	6.2
Other living conditions	198	1.1
Total	18,366[1]	100

[1] The corresponding number of children and young people is 13,759

Group homes for adults

Before 1968, there were only a few group dwellings for the mentally retarded. Between then and May 1973, 146 group homes have been opened, with a total of 1,120 residents. The average number of places per home is thus 8. The smallest number of places at such a home is 3, the largest 19.

40 % of group homes consist of only one flat. The largest number of flats constituting, jointly, a group home is 10 (the average is 2.2). The most common number of places per flat is 4.

The group home is often organized by having one flat as a base flat, from which the other flats are managed by staff. 30 % of group homes are in detached residences or similar, and 70 % in multi-storey buildings.

The number of two-person rooms is about one third of all rooms, the other two thirds being single rooms. Experience has suggested that two-person rooms are to be avoided. If two mentally retarded wish to live together they should have a flat of their own, possibly adjoining the group home.

The original purpose of group homes was to offer adult retarded persons a better alternative than living in a residential home or with parents.

Experience, however, has shown the turnover of users to be high, since this actual form of dwelling seems to create greater independence and an ability to get by in the community. Thus about one third of those so far moving into such homes, have moved, alone or with another person, to a private flat, often adjoining the group home. In total, own residence has been established for some 1,000 adult retarded persons during the years in question, in addition to the 1,120 living in group homes.

The spread in daily cost of care in the various group dwellings is considerable (from SKr 1.60 for the cheapest to SKr 68 for the most expensive). The average cost is SKr 40 per person per day. There is no correlation between size of home and daily cost of care.

The most common age group to be found in group homes is 25—40 years; those over 40 answer roughly for only half as many, and the same applies to those under 25. Only a few are under 20.

About half of those living in group homes come from residential homes, and 22 % previously lived with their parents. The others come from young people's boarding homes, other institutions, etc.

A decisive factor in group domicile is that the person in question should be able to have an occupation outside the home.

Thus, of those living in group homes 41 % attend day activity centres, 26 % work in sheltered workshops, and 13 % work on the open market. The others have other kinds of occupation.

The number of staff per group home varies greatly depending on the degree of independence of those living there; on average, however, there is one staff member per five retarded persons, corresponding roughly to eight man-hours per person per week.

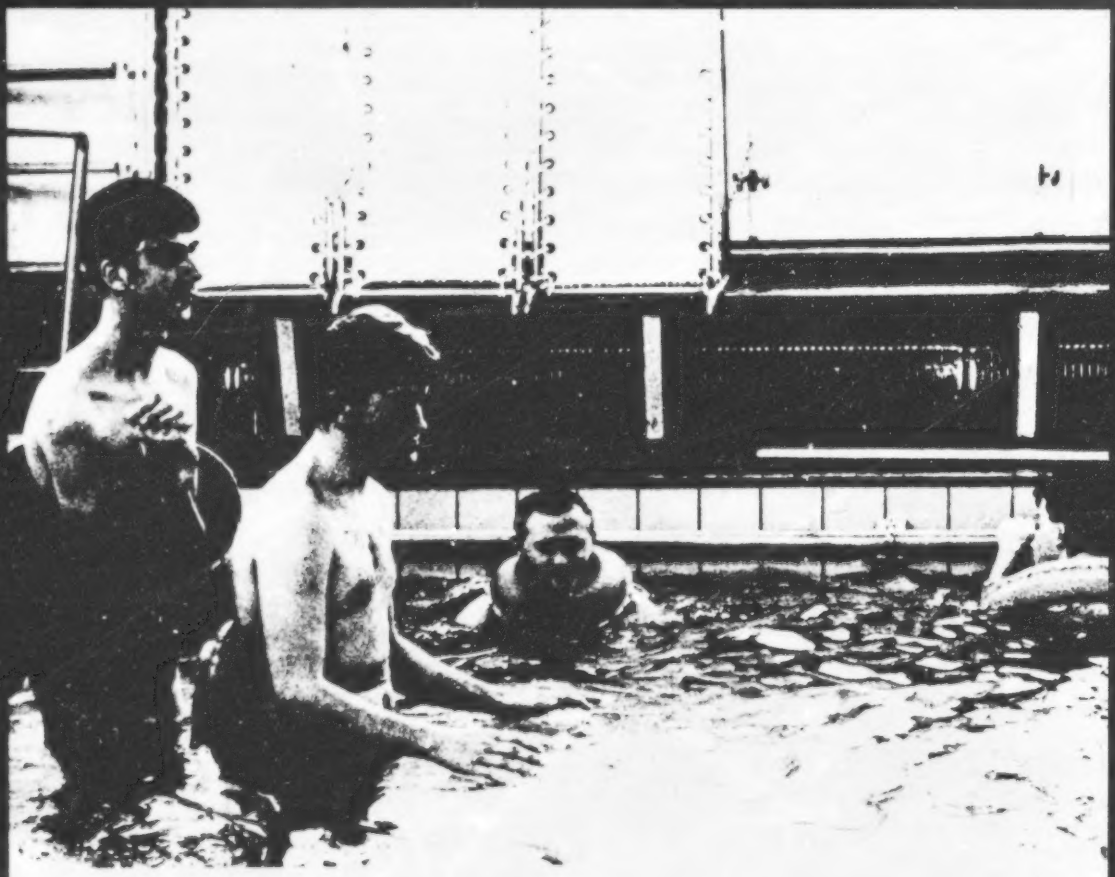
In the early years, certain difficulties were experienced in opening such group homes. The risk of negative reactions has proved to be least in areas with a low neighbourhood group integration, and a low degree of ownership feeling. The decisive factor, however, is the size of the group of retarded persons to be integrated; also, things are naturally easier with children than with adults. We have gradually cut down the size of groups over the years, and it is now usually a question of three to five persons.

We have also learned something of the information that must be provided to neighbours. Unfortunately advance information has the greatest effect on those already positively disposed. There is a major risk that such information will create a special image of the mentally retarded, or actually aggravate people's prejudices. It is therefore important to adapt the amount and type of information provided.

Many prefer to give information only in conjunction with the actual move to the district. The best results seem to be achieved by general advance information, plus mediation of the contacts that the retarded themselves can give their neighbours in conjunction with occupancy.

Such contacts are greatly helped if the group home is a detached residence or row house; residency in a multi-family dwelling seldom produces any contacts with neighbours. Only in a few instances have the neighbours declared themselves disturbed by the retarded. It has thus been easy to get the neighbours to accept that retarded persons should move in to, above all, multi-family dwellings; this, however, has not led to the making of any social contacts, other than of the "Good morning" type. A decisive factor in developing positive contacts is that the group moving in should be sufficiently small.

In the next few years the number of mentally retarded persons in group homes will be doubled. Also, group homes will be established for more severely handicapped retarded persons than previously. So far, those who have moved into group homes have mostly been mildly retarded, a few moderately retarded. In the future, group homes will also be arranged for moderately retarded persons with physical handicaps. Group homes have proved a realistic alternative to life in an institution, and a good starting point for an even more independent way of life.



A new element — a new experience

Residential homes for adults

Sweden has altogether 130 residential homes, which care for 9,000 retarded adults. 18 of these homes also cater for children. Their size varies between about 10 and 330 places. The average number of places per home is 70.

It is usually the large homes that have special departments for children. It is more or less agreed that a mixture of children and adults is unsuitable, and the general desire is to avoid institutions housing more than 200 persons. A home with, at most, 100 places is preferable in many respects, particularly since only then is it possible really to situate the home in the community.

The average size of departments (wards or units) within the institution is 11.5 persons, and bedrooms are now built only for one or two persons.

At each home there is a chief officer or director, who is approved by the National Board of Health and Welfare. A ten-week course is arranged for the training of chief officers, as a supplement to various kinds of basic training.

Swedish residential homes, including those for children, have been considerably improved during the 60's. A screening made in 1967 showed that approximately 70 % of places were of good or at least acceptable standard. The situation is considerably worse at the special hospitals, where only about 30 % of the places were of acceptable standard.

In principle, residential homes should fulfil the functions of an ordinary home. For this reason, living rooms and dining rooms are attached to each department or unit, which must also have such resources of staff and equipment that retarded persons can be trained to a maximum degree of independence, both socially and in the various activities of daily living. Of particular importance is the design of the premises, and of course the qualifications and training of the staff.

There still exists a group of retarded people who are classified as "difficult to handle" and who usually have in common certain traits of agressiveness, hyperactivity and impulsiveness. Experience shows that the most important factor in the rehabilitation of such persons is living in small groups and increased opportunities for active care, with adequate training from the initial stage up to employment in some form of sheltered activity. In most of the residential homes for adults, up to 100 % of the residents take part in regular day activities, mainly of an industrial or occupational therapeutic character. In homes with relatively many severely retarded, the figure falls to about 70 %.

A group of retarded people who require special facilities are those with severe orthopaedic handicaps. With the improvements now made, and the better technical facilities provided, a considerable number of the orthopaedically handicapped can be cared for at residential homes. Even more important, the number of bed patients has been reduced so that there are practically none at all at the smaller homes, and only a few at the larger.

Each County Council usually has a number of residential homes. To achieve a suitable differentiation in respect of equipment, structure and staff, one of these is usually designated in each county as a central residential home. The others then function largely as annexes to this home.

These central residential homes have, on average, 200 places, the others only 42. 30 % of the annexes are privately owned institutions (although the County Council pays the entire daily charge for care, and also decides which persons should be admitted). 1.3 % of all those at residential homes for adults live in rooms with five or six beds, the others in smaller rooms.

Most of the central residential homes built in recent years have special departments for the long-term somatic care of adult retarded persons. These have been designed like other wards for long-term somatic care, and they cater for the retarded who in adulthood sustain somatic diseases, above all as a consequence of old age. It seems only natural that such persons should be given the opportunity to remain at the residential homes where most of them have lived for the greater part of their lives. The number of chronically ill retarded people is not yet sufficient to fill all the places at these special wards. Instead, these places have been found to meet a natural requirement for the care of the motor handicapped adult retarded, whose condition is in many cases a consequence of their not having received the sort of active care that in the future should prevent such cases.

We know that the latter group will decline in number, as the former geriatric group—those in need of long-term somatic care proper—increases. In fact, we do not calculate with any whole-life bed patients in the future.

Special hospitals

For historical reasons, Sweden has a large number of fairly home-like institutions, but they often lack the necessary resources to deal with severe (multihandicapped) cases.

By the terms of the Act on Provisions for Mentally Retarded Persons, the special hospitals are to function on a regional basis and receive all those in the region in need of special care. The regions are the same as those for physical care. Sweden is divided into seven such areas, with an average population of one million, all of them except one with a medical teaching institution.

At present there are six special hospitals, providing for 13 % of all retarded adults requiring day and night care. The average number of beds in these hospitals is 300.

The majority of hospitals are awkwardly situated and are partially used for mentally retarded persons who do not really require care in special hospitals. They are now gradually being restructured.

The system of regionalization is under review. In the future, special hospitals will not be independent, but will be built as special units directly affiliated to the ordinary regional hospitals. This will create greater opportunities to utilize consultants from regional hospitals and research institutions.

There are also two special residential homes, which receive mentally retarded persons with impaired vision and impaired hearing.

The extent of the regional facilities is decided jointly by the member counties,

but the facilities are owned and run by the county in which they are located. The entire responsibility for the patients rests with the individual counties, both legally and financially.

Patients at regional hospitals can, in principle, always be returned to a residential home. This also means that they will return to the proximity of their home communities. The system is thus reversible.

Apart from long-term care facilities for the groups mentioned above, the special hospital will be able to provide short-term care for periods of a few months. This is intended as a service for the various institutions for care and diagnosis at the county level, for those cases requiring special personnel and facilities during the case study and treatment phases. A large proportion of these comprise retarded persons displaying anti-social behaviour.

Services for retarded persons with anti-social behaviour

The number of retarded persons characterized as being anti-social will depend largely on how actively society helps the retarded person at a preventive stage (so that his uncontrolled behaviour—which may otherwise lead to criminal acts —does not make itself evident). In all counties, the custodial care of this group constitutes a special problem, largely because it includes a small number who require different forms of care and confinement from the majority of the retarded. These include those committing criminal and delinquent acts, sexual offences, arson, etc.

Two characteristics of the mentally retarded exhibiting anti-social behaviour may be mentioned here:

a) Preventive measures in the form of close supervision, the provision of accommodation and employment, and organized recreational activities, achieve greater results with the mentally retarded than with any other group in the danger-zone for anti-social behaviour.
b) Mentally retarded individuals may on occasion commit serious criminal acts, perhaps violent in nature, whereas the treatment which should follow may be quite mild in comparison to what is necessary for a normally intelligent person committing the same offence. This discrepancy between symptom and treatment is peculiar to the mentally retarded.

It is vital that any differentiation within the heterogeneous group of anti-social retarded people should be made with due consideration of the special type of care that is desirable or necessary. At the same time, it is important that the units thus created should not cover population areas larger than a region, since the geographical distance to the retarded person's home community is always an

important and sometimes decisive factor in the social rehabilitation programme. As with all other "psychopaths", some of the mentally retarded in this group require care facilities, at least for some time, with relatively strict forms of custody, in which there are locked quarters with special observation, and special procedures and attitudes on the part of the personnel responsible for the rehabilitation programme. These wards are incorporated in the special hospitals.

Only a few years ago, 900 adults were still under care at our special hospitals on the grounds of anti-social behaviour. Over 400 of these have since been discharged to less restricted forms of accommodation, and a further 100 have been discharged as not mentally retarded, nor even in need of care. We reckon that for Sweden as a whole we need 250 places of this kind, i.e. about 3 places per 100,000 of the population. This category of retarded people has thus decreased considerably.

There are apparently no retarded persons in any Swedish prison, nor in any of the special departments at mental hospitals.

The standard of residential facilities

In 1971 the Swedish National Board of Health and Welfare made a survey of the standards of all residential facilities for the mentally retarded in Sweden. The following data were reported:

— number of bedrooms
— number of beds per room
— number of residents per room
— sex of residents
— age

According to the survey there are 344 residential facilities in Sweden with an average of 50 beds. There are 17,200 beds in 9,000 rooms, which means that the "mean room" has less than two beds (1.9 bed).

Table 10. Percentage distribution of the number of beds per room

Beds per room	%
1	48
2	34.1
3	8.9
4	5.4
more than 4	3.2

Table 11. Percentage distribution of the number of persons per unit[1]

Persons per unit	%
1—6	24.9
7—12	44.0
13—18	20.0
more than 18	11.1

[1] A unit is defined as "the smallest ward unit with own day room/living room". The average number of persons per unit was 11.

Care at home

The present trend is to offer increasing help to parents, by counselling and various types of daytime activity. This can prevent final placings in institutions, placings which can be unfortunate both for the parents and for the children themselves. Particularly in the formative years, it is surely essential that mentally retarded children should have the opportunity to be together with other members of the family, and to establish contacts with the community at large.

In the case of adults, on the other hand, the object—following the principle of normalization—is that the retarded person should be able to move to a boarding home or own flat, perhaps with certain supervisory care by relatives or staff from the Board for Provisions and Services to the Mentally Retarded.

The Provisions Act states that if a mentally retarded person needs care but should not receive it at an institution, then the Board should provide the necessary care at his home. In this respect, the mentally retarded are pioneers. They are the first group for whom such a radical enactment has been introduced.

By care at home is thus meant regular visits by various personnel (medical staff, homemakers, occupational therapists, speech therapists, physiotherapists, social workers, etc.). There is also the separate teaching that can be given to children at home. Every effort is made to coordinate the various activities with those run by bodies outside the competence of the Board for Provisions and Services. All County Councils pay a special allowance to the relatives of adult retarded persons who stay at home, and to the parents of severely injured children (see p. 51).

The effect of increased support to parents, both financially and from staff, has been very noticeable. Parents are now much more willing to keep the child at home (sometimes with interruptions for short-term institutionalization), and only a few County Councils now have waiting lists for admission to an institution for children. As regards daily activities, less than 100 children between the ages of 7 and 16 live at home without participating.

Care in other private homes

The care of mentally retarded children in other families than their own has proved a valuable alternative to institutional care. A child who has been a burden in his own family can be an asset in another family. About 500 children and young people are placed in foster homes, but it is a difficult system to develop and it is unfortunately often more rational to place the child in an institution—although seldom preferable, unless the child is in need of special help. The greatest obstacle is that the parents find it difficult to accept that care should be

given by another family, but this is a matter of psychology, and can be overcome.

The number of adults living in "other private homes" is 560. This figure has fallen sharply in the last few years, as we are trying to avoid this type of accommodation.

Day activity centres

Day activity centres for adults have become very popular in the last few years. Their number has increased, and differentiated forms of activity have developed. There are now 110 such centres, not attached to any institution, with 2,200 places (i.e. with an average of 20 places). The smallest of these centres accept 10—12 persons, the largest about 60. There are also, of course, day activity centres at all residential homes and special hospitals.

Of those spending their days at centres integrated in the community, two out of three live with their parents or other relatives, and 15 % in group homes. Together they comprise 12 % of all adult retarded persons receiving services.

The emphasis is on traditional and industrial occupational therapy, and to an increasing extent on ADL training, social training, motor training and adult education. A few people at the day centre cannot take part in organized activities for any length of time, and spend their time there mainly as part of their daily care; no retarded adult is thus too severe a case to be admitted to a day activity centre.

Even if day activities have a certain effect as regards occupational training, and a few trainees can subsequently be transferred to sheltered workshops, the main object is to develop an independent and harmonious personality. Most of those attending a centre receive a certain compensation, which varies between SKr 3 and 10 per day on top of their pension.

A few young people attend day activity centres as early as at the age of 17 or 18, but the intention is to provide such occupational training as they need at a special school for young people.

Sheltered workshops

Sheltered workshops for the mentally retarded are geared entirely to production, and the only systematic training given is occupational. There are 38 sheltered workshops in Sweden for 1,100 retarded people, corresponding to roughly 30 persons per workshop. In addition to this, some 600 retarded persons have been individually integrated in the work of ordinary sheltered workshops. 10 %

of the adults receiving any form of service work in sheltered activities. 43 % of those working in sheltered workshops live with relatives, 17 % in residential homes, 18 % in group homes, and 20 % in their own homes.

We have previously built a number of sheltered workshops in direct conjunction with residential homes, but we discovered early on that this was a mistake; instead, we began to attach sheltered workshops for retarded people to similar facilities for other handicapped. The majority of such workshops are thus part of a larger unit, which gives better opportunities for gradually sluicing in the retarded among other handicapped persons.

Considerable numbers of retarded people have now been transferred from sheltered workshops to day activity centres, since the demands made in respect of performance have increased at the sheltered workshops, and many retarded persons have had insufficient systematic training in work. Another reason, however, for these transfers is that adequate technical aids have not yet been developed for the retarded. At the same time, experience has shown that many of these borderline cases note a better personality development if they can spend their days at activity centres.

Own work

The Board for Provisions and Services to the Mentally Retarded is required to assist retarded persons to obtain a job of their own, if they can handle it. Many can then be left without supervision by the Board, while 1,500 of those independently employed still receive help. 43 % of these live with relatives, 31 % have own accommodation, 11 % live with another family, and 9 % in group homes.

Sweden has no quota system by which employers are required to employ handicapped persons. The state, however, pays 40 % of the wages of any handicapped person employed. On the other hand, this offer has not as yet had any great effect, even though it applies also to a person already employed who incurs a handicap.

Leisure activities

Leisure activities have developed over the years to become a major aspect of the provisions made for retarded persons. This, obviously, applies above all to those living at residential homes and special hospitals. There is continuous discussion as to what proportion of activities should be specially arranged for retarded

people, and what proportion can be integrated with the regular activities of the community.

Over the years, there has been a considerable shift of adult education and other methodical group activity from leisure activities to day activities.

Particular attention has been paid to the need for leisure activities on the part of young people living at home, and of those living at group homes for adults. Even so, this need has not been satisfactorily met. If an adult retarded person fails in his domicile at a group home, the failure can usually be ascribed to his leisure, and activities outside the home.

Individual rights, costs and supervision

Care as a right and obligation

A mentally retarded child who can avail himself of teaching—and this, according to the National Board of Education, means all retarded children—is obliged to attend school from and including the age of 7 for as long as instruction is required, although at most to the age of 21 (in exceptional cases 23).

If it is necessary for geographical reasons, or owing to home conditions, that the pupil should live at a boarding home in order to avail himself of teaching, then the director of the special school can decide to this effect.

A mentally retarded child under 15 who needs care at a residential home or special hospital can be given such care only with the consent of his parents or legal guardian, or if the child has been committed to care in accordance with the Child Welfare Act.

A person of 15 or over can be committed to a residential home or special hospital without his own consent, or that of his parents or guardian. It must then, however, be certified that care is absolutely necessary in view of the severity of the retardation, and that the person concerned:

a) constitutes a danger to the personal safety, physical or mental health of another person, or to his own life,
b) is incapable of looking after himself,
c) is incapable of protecting himself against sexual abuse, or
d) behaves in a manner gravely disturbing to persons living in the vicinity, or others.

Also, a court of law can commit a mentally retarded person of 15 or over to a special hospital. Naturally, every attempt is made to keep care on a voluntary basis. No one can be forced against his will to enroll at a group home for adults, a day activity centre, or a sheltered workshop.

Formal procedures

Parents do not have to write any sort of report or application for their children to be enrolled at a special school or other. If the child has reached the age of 15, his own opinion should if possible be heard. If he refuses, the Decisions Committee can decide on enrollment or otherwise. The same applies if the parents do not consent.

For enrollment at a special school, residential home or special hospital the usual requirements are a medical certificate and a psychological, pedagogical and social investigation of the case.

If the parents agree — and the child concerned if he is 15 or over — a pupil attending an ordinary school can be transferred for a short period to a special school without any documents being required. These can if necessary be made out later at the school.

Officers of the Board for Provisions and Services to the Mentally Retarded are required to assist in obtaining the necessary documents, or if necessary writing them out themselves.

Who decides?

The principle is that a decision can cover only one type of service. New formal decisions must thus be made in the case of transfers.

Enrollment at a special school is decided by the director of special schools for the mentally retarded, after consultation with the medical director of the Provisions Board.

If it is considered that a pupil at such a school should be transferred to another form of schooling at the same institution, for example to a training class, then the parents or guardian of the child should be given an opportunity to comment. If the pupil has reached the age of 15, then his view should also be heard if possible.

Enrollment at a residential home is decided by the director of care for the mentally retarded, after consultation with the Board's medical director. Enrollment at a special hospital is decided by the doctor in charge of the hospital.

Decisions by the directors, as mentioned above, must not run counter to the

applicant (or to the retarded person himself if over the age of 15); in such case enrollment shall be handled by the Decisions Committee.

The director of care decides on enrollment at day nurseries for children, day activity centres and in group homes. He also decides on placing persons in other private homes, and on home service. None of the latter forms of care can be given contrary to the wishes of the retarded person or his guardian.

On discharge from one form of service it shall be considered what other care should be provided for the person concerned in accordance with the Provisions Act.

State nursing allowance and basic pension

On the initiative of the Swedish National Association for Retarded Children, children under 16 living at home are entitled to a nursing allowance if they need special supervision and care for a considerable time and on a considerable scale, by reason of a physical or mental handicap. Mentally retarded children below the age of 3 are entitled to a nursing allowance only if the disorder is extremely severe, or combined with some grave physical handicap. The same sort of allowance is paid to the children cared for at boarding homes or residential homes (provided they stay at the home for a period of at least two consecutive weeks).

The nursing allowance amounts at present to SKr 8,505 per year. About half of all children receiving such a grant suffer from other handicaps than mental retardation.

Practically all retarded people who receive services and are over the age of 16 draw a state invalid's pension. This pension amounts to the same sum as the nursing allowance, SKr 8,505. Certain supplementary allowances are made for, among others, those with orthopaedic handicaps.

The costs of care

The care provided for a mentally retarded person shall be free of cost to both the retarded person himself and the parents. By the terms of the Provisions Act, however, reasonable charges for board and lodging can be exacted from an adult if he has an earned income, and not a full disability allowance.

Free care covers teaching material, text books, school meals, necessary daily travel to and from school, day nurseries for children, day activity centres, dental care, speech therapy, physiotherapy, and such other health and medical services as can be provided at the facility concerned.

If the retarded person lives at a group home, boarding home, residential home, special hospital or, at the cost of the County Council, in another private home, then he shall also receive the necessary medical care, and reimbursement for travel to visit his parents once a month. If he is under 21 and cannot utilize his right to such travel, then it can be transferred to the parents, or to a guardian, relative or friend so that they can visit.

The County Council has the right to collect the children's allowance, advance allowance or basic pension of a mentally retarded person living at one of the facilities mentioned by the Provisions Act. The children's allowance is currently SKr 1,500 per year and the basic pension SKr 8,505 per year. In addition, there is a state grant to the County Councils of about 1/20th of the running costs and 95 % of all the teachers' salaries.

There are 45 private residential homes, enrollment in which is decided by the same persons as decide on enrollment and discharge at the residential homes run by the County Councils. The daily charge for care is decided by the County Council in which the home is situated, and paid for by the County Council in which the retarded person was domiciled.

Pocket money

To those drawing a basic pension and living at a home or hospital, the County Council pays at present at least SKr 213 per month in pocket money. The Board for Provisions and Services has the right to decide on a reduction of this sum if the condition of the person concerned clearly makes it impossible for him to benefit from the entire sum. The more active and more socially directed the care given, the greater opportunity the mentally retarded has to use his pocket money. If he cannot make use of a cash sum, then the corresponding amount of money shall be used to increase his sense of well-being, or otherwise for his personal benefit. The majority of mentally retarded receive the maximum sum.

Pocket money is also paid to children in residential homes and schools, on a rising scale in relation to their age.

Technical aids

Retarded people have the right to practically all technical aids. Even so, it has proved difficult to get such aids distributed and used at the institutions to the same extent as with other handicapped persons. Sometimes the aids in question must be simplified slightly, and a longer period of training is usually involved. Descriptions are lacking, and there is a shortage of special pedagogic staff—above all physiotherapists—needed to instruct staff and parents.

A list has been published in Sweden of the international technical aids available (see ref.).

Professional secrecy etc.

Those who are or have been active in the care of the mentally retarded as provided for in the Provisions Act are required by law to observe discretion regarding the information they possess concerning the lives of private individuals, especially with regard to their parents and family circumstances. This applies to all persons—officials, politicians, trainees and others—who acquire information concerning the personal circumstances of mentally retarded persons.

The staff at institutions for the mentally retarded are not permitted to trade or barter with those receiving services, nor to accept other gifts than those lacking any real economic value. Nor may personnel allow mentally retarded persons to perform work for them. This, however, does not apply to "helping out" at the institution, or performing temporary errands etc. for the staff, which can be an important aspect of social training.

Supervision

The main supervisory authority for special schools for the mentally retarded, and for boarding homes catering for such pupils, is the National Board of Education. The National Board of Health and Welfare supervises medical activities at such institutions, and is the main supervisory authority for care in general. The Boards, i.e. the state, are not responsible for the running of any institutions or hospitals for the mentally retarded, with the exception of two schools for deaf and blind retarded children.

The plans drawn up by the various County Councils to implement the legislation are approved by these two central Boards, as are the architects' drawings for buildings, the number of places, the qualifications of senior officials and administrative staff at the institutions, etc. The Boards regularly inspect and report on all institutions—the Board of Education mainly through its county organizations.

An important aspect of the work of these central authorities is to publish various standards, and to arrange courses and conferences for those providing the various services. This, however, does not include the actual basic training of such staff. Particularly important are the conferences arranged for politically elected members of the Boards for Provisions and Services for the Mentally Retarded.

A more direct influence on planning can be achieved when representatives of the two central Boards confer with the county Boards for Provisions and Services. This gives the former wide scope in initiating and controlling the planning process.

At government level, of course, the two central Boards represent the opinions of the county organizations for the purposes of committee work, statistical studies, etc.

Local supervision—including the inspection of activities not associated with residence, and of private activities—is exercised by the local Board in the county concerned. The members of the Board are to acquire a personal knowledge of activities at the various facilities, and the Board shall also appoint one of its members to visit each facility at regular intervals, and make himself acquainted with conditions there.

Legal incapacity

Even mentally retarded persons become legally competent on attaining their majority, unless they are declared legally incapable by a court. Such a declaration can be made in respect of persons who according to a certificate by a psychiatrist are "incapable of managing their persons or property by reason of mental disease, mental retardation or other mental disorder".

This system does not provide for the new forms of personal supervision that many adult retarded persons can now obtain, and the legislation on guardianship is therefore under revision.

On marriage

Swedish legislation no longer incorporates any general impediment to marriage on the part of retarded persons. If the person concerned understands the legal implications of marriage, he is also entitled to marry. Those with a guardian, however, must obtain their guardian's permission. If such permission is not forthcoming, the case ban be considered by a court.

The entire question of marriage has been seen in a different light since, in recent years, it has been generally recognised in Sweden that adults can live together without being married.

Various studies made in Sweden have brought to light the following:

a) that retarded women marry more often than retarded men;

On the way home from work — like everyone else

b) that the retarded very seldom marry each other;
c) that retarded women bear children only half as frequently as non-retarded women;
d) that retarded women (when they *do* have children) have more children than the non-retarded;
e) that in the case of retarded women there is a major difference between being able to handle one child and several;
f) that retarded women have retarded children only slightly more frequently than the non-retarded.

On sterilization

The 1941 Act on Sterilization stipulates that persons who can be expected to pass on hereditary mental illness or deficiency to their children can be sterilized, as can persons who by reason of mental retardation are considered clearly unsuitable to have custody of children in the future. This Act is on a voluntary basis, and presupposes the consent of the person concerned. Those, however, who are incapable of giving their valid consent owing to mental disorders can be sterilized without their consent. This latter possibility is used very restrictively.

Since the early 50's, only very few retarded persons have been sterilized—in the last ten years only about 30 persons per year. The Act on Sterilization is for various reasons under review.

There are several reasons for this restrictive policy. It is very difficult to judge in advance which mentally retarded persons, of those for whom the question of sterilization arises, may later in life become capable of managing parenthood, and which will not. Sterilization is a definitive operation, which cannot be reversed if the person concerned should subsequently mature and it is often psychologically traumatic. There exist at present other ways of preventing undesirable pregnancies, for instance counselling on birth control and contraceptives.

Special status in criminal law

The Swedish Penal Code states that a person reaches the age of criminal responsibility at 15, from which time onwards he can be tried for offences before a court of law. Mentally retarded persons are no exception in this regard. Following the policy of normalization, it is increasingly frequent for the mildly retarded to be treated like other citizens in this respect—as, indeed, is their human right.

A person, however, who has committed an offence as the result of mental retardation must not be sentenced to prison. The court can decide to commit a mentally retarded person for care at a special hospital, if it finds—after special psychiatric examination—that the retarded person needs such are.

Relations to other services, personnel training and the future

The Swedish National Association for Retarded Children

The first local parent association was formed in 1952, and the National Association in 1956. The latter now has around 14,000 members, in 110 local associations. After having previously operated day facilities of different kinds (these have now been taken over by the County Councils), its main function—apart from acting as a pressure group—is to provide information to parents, often with the help of specially trained parents' advisors.

Lippman (see ref.) notes that probably no other country in Europe than Sweden assigns such a marked role as a pressure group to the National Association. This applies above all to political pressure.

The Association has a differentiated programme for the training of parents, covering the compilation of suitable literature designed above all for use in study circles (as a rule ten evenings, in small groups). The following categories of parents have specially designed material available:

a) parents of retarded infants,
b) parents of children with multiple handicaps,
c) parents of children in the early school years,
d) parents of teen-agers,
e) parents of retarded adults.

One activity launched by the National Association is that of "toy libraries", mainly for the use of parents with children under school age. The object is not only to try out suitable, and stimulating, pedagogical toys, but also to find out what special difficulties the children encounter. Great importance must therefore be assigned to having an adequatly trained "toy librarian" available.

There is also a Nordic association (NFPU), mainly for professionals, which runs conference activities and publishes the journal *Psykisk Utvecklingshämning*.

Staff and experts

Until the mid 50's, resources of qualified personnel were split between the pedagogic staff at special boarding schools and the medical staff, mainly at certain hospitals. Care was also provided at a fairly large number of small residential homes, mainly in accordance with a social model.

Cooperation in a team is now statutory, and the social model has been supplemented with teaching and medical care.

Sweden, however, has fairly few full-time doctors by comparison with certain other European countries. There is no medical specialty in mental retardation, and the majority of doctors employed on a full-time basis (about 40) are usually specialists in adult or child psychiatry.

The number of social workers in this field in Sweden has increased strongly in the last ten years or so, and the number of psychologists has risen ten times over in the last five. There is still, however, a considerable shortage of physiotherapists and trained occupational therapists, and of speech therapists.

The role played by the experts in rehabilitation has been a subject of great discussion. A general opinion is that the ability of the experts themselves, in the actual course of their work, to influence retarded people has been overestimated. There is a risk of the expert becoming too concerned with his particular task. Also, technical efforts have been overestimated at the expense of personal and emotional contacts. These judgements apply particularly to the big institutions.

The object today is that the experts should adapt themselves more to the team, and work through the base personnel, with the retarded himself in the centre. We are aiming at an "individual-centred model".

Training of nurses for care of the mentally retarded

The curriculum for this type of nurses has for many years been as follows: 20 weeks basic course in care of the mentally retarded, 52 weeks professional work, and 22 weeks vocational course in care of the mentally retarded.

Table 12. Different lines of the secondary school's two-year nursing course

<table>
<tr><th>Term</th><th colspan="5">Lines</th></tr>
<tr><td>4</td><td rowspan="2">Line for General Nursing and Care of the Aged</td><td rowspan="2">Line for Psychiatric Care</td><td rowspan="2">Variant for Care of Adult Mentally Retarded</td><td rowspan="3">Line for Child and Adolescent Care</td><td rowspan="3">Variant for Care of Sick Children</td></tr>
<tr><td>3</td></tr>
<tr><td>2</td><td colspan="3">Line for General Nursing and Care of the Aged</td></tr>
<tr><td>1</td><td colspan="5">Joint instruction</td></tr>
</table>

Roughly half of the nurses employed have undergone half or all of this programme.

A new upper secondary school for young people was introduced in 1971. One of the 22 courses of the school is a two-year nursing course. Qualified students acquire a competency approximately equivalent of that of a senior student nurse.

Young people wanting to work among adult mentally retarded choose the line for psychiatric care, during their second year at the school. This line has a special variant for such studies.

Young people wanting to work among retarded children can either follow the line for child and adolescent care or a variant of this line for the care of sick children.

Teachers

Teachers are to have a regular basic training, plus—as a rule—one year's special training. For the past year or so, there has been a special line of training for the teachers at training schools. Special teachers enjoy a somewhat higher salary than other teachers, but they are still in short supply. There is a particular shortage of training-school teachers.

Child psychiatry

To give something like an overall picture of the care provided for the mentally retarded, some mention must be made of the County Council's other activities in allied fields. This applies particularly to cooperation with the medical system for the mental care of children and young people. Departments of this type (with facilities for in-patients) are now available in all counties and County Boroughs. Mention should also be made of three special hospitals (departments) for mentally sick children and young people, each with up to 50 beds, and a number of residential homes for psychotic, not mentally retarded children.

Many mentally retarded children are "discovered" by the child psychiatry departments, and treated there before being transferred to the services run by the Board for Provisions and Services to the Mentally Retarded. There is nothing to prevent them from being transferred for further observation, diagnosis and treatment.

Pediatric departments

There is at least one medical department for children in each county. It is usually at these that the relatively most retarded children are first diagnosed, many of them in the maternity wards.

Our policy is that the child should be cared for at a medical department only if he needs medical care, otherwise everything should be done to provide care at home.

Cooperation between the services provided by the Board for Provision and Services and by the children's hospital is usually adequate, but it still happens that the Board's staff are coupled into the situation of the family or the child far too late.

Psychiatric departments

Mentally retarded persons run a greater risk than the normally gifted of suffering from various mental disorders. The treatment of such states in retarded persons does not differ in principle from that accorded to non-retarded patients. Retarded persons suffering from a mental disease should therefore be treated at the regular psychiatric hospitals or departments for as long as treatment is concerned mainly with the illness.

Research

Very little basic research is at present initiated in Sweden from the starting point of mental retardation. On the other hand, a great deal of basic research starting from other premises is relevant, above all, to the prevention of mental retardation. Applied research is being performed on different methods for the rehabilitation of retarded persons, from the pedagogic, medical and social aspects. Three groups, mainly comprising psychologists, are concerned with research in this field, namely the Kylén group in Stockholm, the Kebbon group in Uppsala, and the Liljeroth group in Lund.

The future

The following three factors have been decisive for the development of provisions for the retarded in Sweden:

a) A deeply rooted respect in the Swedish population for the value and potential of each individual, even if he or she cannot participate in production.
b) A real conviction that the mentally retarded can be helped.
c) The fact that the public sector bears the total social responsibility for those citizens in need of help.

We are now in a position to take the step from the stage of differentiation to that of decentralization and integration. How far is it possible to combine the more specialized care of the mentally retarded (which can lead to relative isolation) and efforts coordinated with other forms of service to handicapped and non-handicapped persons (which can complicate penetration of the retarded person's specific problems)? This is a delicate balance, which demands sensitive attunement to various trends in development. The retarded individual should be regarded only as one among all others who needs some form of support or service.

It is not enough to normalize the retarded person, we must also normalize our services and the entire organization of services. In reality, the retarded are part of the total community and they can help us in a process of de-intellectualization as a counter-balance to the over-intellectualization we observe today.

One does not have to work with the care of mentally retarded persons in Sweden for long in order to observe how rapidly attitudes to handicapped persons have changed—in a positive direction. The different political parties and government offices all overbid each other in setting priorities in favour of the handicapped. Many private persons make active personal contributions and a favourable attitude towards the handicapped confers social status.

However, the rights and obligations constitute only the outer framework. The actual content of care must in reality reflect the more far-reaching and thus also more essential right of the mentally retarded to be accorded full value as a human being.

It means also that retarded children and adults must be allowed to express their will and make their own free choices in all the small, everyday situations that are a matter of routine for us, but to them can mean the beginning of independence.

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Vocabulary

arbetsterapeut	occupational therapist
beslutsnämnd	Decisions Committee
centralt vårdhem	central residential home
dagcenter (sysselsättningshem)	day activity centre (for adults)
daghem	day nursery
elevhem	boarding home (for schoolchildren)
fosterhem	foster home
fritidsledare	leisure time supervisor

fritidsverksamhet	leisure time activities
förskola	preschool
hemmavård	care at home
inackorderingshem	group home (for adults)
Lag angående omsorger om vissa psykiskt utvecklingsstörda	Act on Provisions for Certain Mentally Retarded Persons
landsting	County Council
lekotek	toy library
län	county
omsorger	provisions and services
omsorgsstyrelse	Board for Provisions and Services to the Mentally Retarded
regionsjukhus	regional hospital
sjukgymnast	physiotherapist
sjukvårdsregion	hospital region
skyddad verkstad	sheltered workshop
socialdepartementet	Royal Swedish Ministry of Health and Social Affairs
specialsjukhus	special hospital
specialsärskola	special boarding school for retarded children with behavioural problems
särskild undervisning	separate teaching
specialundervisning	special teaching
specialvårdhem	special residential home for multiple handicapped retarded persons
särskola	special school
särskolchef	director of schools for the mentally retarded
särskollärare	special teacher
talterapeut	speech therapist
träningsskola	training school
utvecklingsstörd	mentally retarded, mentally handicapped
utvecklingsstörning	mental retardation
vårdchef	director of care
vårdhem	residential home (for children and/or adults)
yrkesskola	vocational school (for the mentally retarded)
yrkesträning	work training
yrkesundervisning	vocational training
yrkesutbildning	vocational education
yrkesvalslärare	vocational guide
överläkare	medical director

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